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Tel: 0844 249 0228 or email dnsbs@servicehelpline.co.uk

UK – 12 issues: £24.00, 24 issues: £40.00, 6 issues direct debit: £10.00. **Europe** – 12 issues: £33.00, **World** – 12 issues: £35.00, **Eire** – 12 issues: £33.00

ALTERNATIVE FORMATS

Disability Now is also available on cassette, disk or via email from Talking Newspaper Enterprises

Tel: 01435 862 737; tnauk.org.uk

Published by Scope, a registered charity,
no 208231. © Scope 2011

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Publishing, production and distribution management by FuturePlus. futureplus.co.uk

ISSN 0958-4676



EDITORIAL ENGAGEMENT FOR BRANDS
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editorial

Finding out the hard way

In the next issue of this magazine we're planning to feature a profile interview with PC David Rathband. Back in the summer, you may remember, he was on duty with Northumbria Police when he was shot in the face by fugitive gunman Raoul Moat. As a result he lost one eye and all of his sight.

Without wishing to sound, or indeed, be callous, listening to what someone like him – new to our community, new to the disabling experience – has to say can be an informative and salutary experience. He proves to be a thoughtful and perceptive man, particularly when asked questions which go beyond the obvious or banal.

Naturally he rails against what has happened to him. Equally naturally he rails against the physical frustrations, the mental anguish and trauma he's undergone.

But much more interesting and revealing is his take on his reception into the blind/the disabled community.

For a start, he is, by and

large, not greeted by people like him. Instead he encounters mobility and rehabilitation professionals either from charities or local authorities who think they have what he needs. Of course, as he's quick to tell us, they don't.

Equally telling is the speed at which David Rathband recognises the reality of the disabling experience. While it's obvious that, despite the best efforts and intentions of his professional visitors, the sheer practicalities of being blind aren't swept away by what they offer, what he recognises with equal clarity are those other attitudinal barriers which affect the way in which he, as a blind man, is now regarded and treated. He's struck by just how little the charities do to tackle those barriers or empower him to meet and overcome them, indeed how little they are concerned or engaged with them at all.

• Read our profile of PC David Rathband in the March issue of *Disability Now* out at the end of February.

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newsview

Falconer commission's loaded agenda

In *Disability Now* last month, Lord Falconer, who chairs the Commission on Assisted Dying, talked about what he saw as the need to clarify the law on assisted suicide.

As the law stands, although it's currently an offence in English law to help someone to die, a person may not be prosecuted for doing so.

Kevin Fitzpatrick, a member of the Not Dead Yet UK campaign, disagrees.

He thinks there's no need to change the law on assisted suicide because it both provides safeguards for disabled people whose lives might otherwise be at risk, and allows people who want to choose to end their lives to do so.

Fitzpatrick dismisses the



Kevin Fitzpatrick, of the Not Dead Yet UK campaign, talks to **Sunil Peck** in response to last month's interview with Lord [Charlie] Falconer. He questions the agenda of the Commission on Assisted Dying and says that any changes in the law on assisted suicide would endanger the lives of disabled people

“If we stay silent on individuals' choices it's not because we don't feel those issues very keenly: we do, of course, [but] there's a big difference between the compassion we all feel for individuals and a general change in the law”

idea that changing the law would eliminate the need for people to travel to Swiss clinics like Dignitas to die, and that it would remove the threat of prosecution from those who help them to do so.

People don't need a law change to discourage them from using Dignitas, he explains. “They already have the choice to die legally at home in this country. They can refuse treatment or ask for it to be withdrawn and to be kept comfortable.”

It's important, says Fitzpatrick, that individual cases of people going to Switzerland to die should not be used to promote the cause of changing the law.

“If we stay silent on individuals' choices it's not because we don't feel those issues very keenly: we do, of course, [but] there's a big difference between the compassion we all feel for individuals and a general change in the law. Not Dead Yet opposes the idea that there should be a

change in the law.”

Although there's a debate around the issues involved with assisted suicide, the Commission on Assisted Dying has no legitimacy to lead it, according to Fitzpatrick, because its neutrality is in question.

The Commission is partly funded by the author Terry Pratchett, who has campaigned to legalise assisted suicide. Lord Falconer, its chair, is an advocate of assisted suicide. And the majority of ➔



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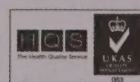
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INVESTOR IN PEOPLE

its members are also known to favour assisted suicide.

“What they’re doing, it seems to me, is searching for an evidence base to support their argument that there should be a change in the law,” says Fitzpatrick.

For this reason, Not Dead Yet says that it will refuse any invitation to give evidence to the inquiry, if invited to do so.

“We do not want to do anything that gives credibility to a one-sided and loaded special interest group,” he explains. This raises the question of how,

in that case, Not Dead Yet wishes to contribute to the debate.

“The ideal position is that everyone who is afraid of suffering at the end of their lives should have that fear removed. They should have clear unequivocal access to the support services they need to convince them that they will be made comfortable throughout the process.

“What we now have is a fear of suffering, and this won’t improve with a change to the law. If the law does change, the lives of disabled people will be

put at more risk.”

To stress the point, he adds: “We already have safeguards in place. In recent court cases, a mother [who had helped her daughter to die] didn’t go to prison because it was clear that she had done everything to convince her daughter not to want to be helped to take her life.

“In another case, another mother who was implicated in inflicting damage on her son did go to prison.

“The law currently protects not just disabled people but everyone from that kind of

harm from family members, carers, including health professionals and anyone else who has a mind to commit euthanasia.

“That protection must be reinforced, not removed at a legislative stroke.”

“What they’re doing, it seems to me, is searching for an evidence base to support their argument that the law should be changed”

Who's the WINNER?

Thanks to all those of you who took the time and trouble to complete our recent reader survey. The response was much bigger than we expected and we'll be using all the information you provided to help us make *Disability Now* even better and give you more of what you want.

One lucky reader will receive £50 of Amazon vouchers.

Congratulations to: **Alan Cole of Stoke on Trent.**

Enjoy your prize.

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Nazi death programme bodies found



Annie Makoff

The remains have been uncovered of what appear to be 220 disabled victims of Nazi Germany's notorious Aktion T4 programme, in the grounds of an Austrian psychiatric hospital (above).

The bodies, discovered by a construction firm digging on the site of the institution near the town of Hall in the Tyrol, were examined by experts who have confirmed that the burials took place between 1942 and 1945 and are likely to be those of disabled and mentally ill patients.

Until now, it was thought that Aktion T4 murders in Austria were confined to just one so-called "hospital"

but the discovery of the Tyrol mass graves suggests that the programme was more extensive.

Aktion T4 was the Nazis' term for a euthanasia programme that sought to "cleanse" the "master race" of disabled and mentally ill people and those with hereditary and incurable diseases. Though on a much smaller scale, it's often seen as paralleling the extermination of Jews.

Men, women and children with an illness or disability became victims of the programme. Medical staff throughout the Third Reich were instructed to hand over disabled or sick babies to the authorities.

Liz Crow, founder and

director of creative media company Roaring Girl Productions (currently touring with their film *Resistance*, specifically about the Aktion T4 programme), said: "The scheme was the Nazis' first official programme of murder.

"It targeted disabled people and became the blueprint for the Final Solution to wipe out Jews, gay people, gypsies and other social groups. As with the majority of disabled people murdered in this way, it's unlikely we'll ever identify the people exhumed from Tyrol's mass grave."

Richard Rieser, founder of Britain's first Disability History Month, believes that thousands more disabled

people were murdered under the scheme than has been admitted to.

"There were at least six castles and about 40 hospitals in Germany that practised Aktion T4," he said, "so I'm not surprised that more graves are being found elsewhere. The German government has put the number of Aktion T4 victims at 250,000 but the likelihood is that the number is significantly more.

"Even when the Americans walked into hospitals across Germany in 1945 and 1946, the murders of disabled children and adults were still continuing."

He added: "This gives us pause for thought. We know very well that there are still plenty of people who hold the view that disabled people are unworthy of life, as the Nazis deemed us. This is why it's so important to understand what happened, and for it to be a part of history that everybody learns from, so mistakes of the past are not repeated."

The Austrian government has vowed to conduct a thorough investigation into the discovery. Current construction work on the former hospital site has been postponed and the exhumation of the graves is expected to begin in March.



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ruth patrick



CHRIS RICH

Let's talk about **sex**



Valentine's Day is fast approaching, the day when glowing women skip through the streets, arms overflowing with bouquets, and every restaurant is crammed full of smug couples. **Ruth Patrick** feels that now seems as good a time as any to look at issues of sex and disability

Sex and the "right" to a sex life are not easy things to campaign over, and it is perhaps not surprising that the disabled people's movement has often steered clear of high-profile campaigns on the sexual rights of disabled people. Although no one can demand a right to sex, we should aspire to an environment which enables the sexual expression of all,

regardless of disability, age, gender, ethnicity and sexual orientation. Indeed, some do talk in terms of sexual rights, not to sex, but to the opportunity to pursue a satisfying, safe and pleasurable sexual life.

Until 2004, an organisation devoted to matters of sex and disability did exist – SPOD (The Association to Aid the Sexual and Personal Relationships of People with a Disability).

However, SPOD closed due to difficulties in attracting funding, as well as problems getting disabled people on board. Its former director (and *Disability Now* contributor) Simon Parritt, believes that "sexual rights are perhaps one of the last areas where disabled people's organisations have struggled to find an effective campaigning voice".

Today, two linked organisations, Outsiders and

the Sexual Health and Disability Alliance (SHADA), both seek to promote discussion around sexuality and disability. Most recently, Outsiders created a Sexual Respect Tool Kit to help GPs and other health professionals initiate discussions on sex, relationships and loneliness with disabled people. They have also challenged councils to give more consideration to the sexual needs of disabled people. As Dr Tuppy Owens, founder of Outsiders, argues: "It is damaging to disabled people if our sex and relationship needs are not included in consideration of our general needs."

There is certainly scope for campaigning around sex and disability, particularly if we consider the mileage in a social model take on these issues. Just think of the disabling barriers which society erects to the full and equal sexual participation of disabled people. If a wheelchair-user wants to go out nightclubbing to pick up some talent, they will often have to overcome sizeable physical and attitudinal obstacles along the way. Being sexual and glamorous costs money, money which disability benefit claimants may often not have, particularly as this Government continues its great-welfare-robbery!"

There are also ingrained myths around disabled people's asexuality which, as Tom Shakespeare argues, is symbolically represented by providing three types of public toilets – male, female and disabled. When disabled people's sexuality is acknowledged, it is often constructed as threatening, particularly for people with learning disabilities and mental health issues.

So, plenty of work to be done on myth busting and calls for a social model approach to disabled people's inclusion in the

Being sexual and glamorous costs money, money which disability benefit claimants may often not have, particularly as this Government continues its great-welfare-robbery!

sexual life of the nation. And yet...

It is much easier to campaign on ramps and

transport than on personal matters of sexuality. This, in part, may explain many disabled people's reticence to get political about sex. Standing up and loudly proclaiming one's sexuality and demanding greater recognition in this domain certainly takes guts!

However, the fact that it's difficult shouldn't stop us trying. Looking to the future, Simon Parritt argues:

"A campaigning organisation on sex and disability is vital if some light and hope is to be introduced into a world which society at large would like to ignore and which disabled activists, with a few notable exceptions, have avoided."

• For more information on the work of Outsiders and SHADA see: outsiders.org.uk; shada.org.uk

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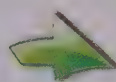
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disabilityrights

Axed fund **threatens** independent lives

It's the news thousands have been anticipating with less than excitement: that within five years, the fund which has kept them out of residential care will be no more. **Sunil Peck** reports

The Government has finally confirmed that it's to scrap the Independent Living Fund (ILF). Users have described the news as a disaster and say that it has the potential to set the lives of disabled people back decades.

The fund was set up in 1988 and now provides money paid by the Department for Work and Pensions (DWP) to more than 20,000 disabled people with high support needs to live independently at home, thereby keeping them out of residential care.

But the Minister for Disabled People Maria Miller announced in December last year that the fund would close by 2015 because it's "financially unsustainable".

But she has so far failed to explain what will replace the fund or how existing users and those disabled people who were prevented from benefitting when the fund was closed to new applications in 2010, would be in a position to continue to exercise any choice or control over their lives after 2015.

Is it really conceivable, for



instance, that cash-strapped local authorities, whose budgets are already being hit by other Government spending cuts, will be in a position to meet the higher costs of care and support packages?

The ILF makes up around fifty per cent of Martyn Sibley's (pictured above left) care package. For eight years it has enabled him to employ personal assistants so he can do things like turn over in the night, dress, cook, clean his flat and socialise with his friends.

Not surprisingly, he's "scared" that the abolition of the ILF will take away his independence and his career.

As he told *Disability Now*: "The crux of the matter is if I can't find anyone to do my care for the amount of money in the



It'll take the lives of disabled people back to the days when nobody had any support and you ended up in a Leonard Cheshire home

coffers. I'd have to give up my job and move back home and rely on friends and family instead."

As another user of the fund, Sian Vasey (pictured above right), puts it: "If you need help with getting up, going to bed and preparing and eating food, you have to be able to pay people. Very few disabled people have people who can do that work for nothing; it's ongoing and regular labour that's needed."

Sian is also Director of the Ealing Centre for

Independent Living (ECIL), and says that her local council in west London will see a 28 per cent reduction in funding from the Government. But it's making cuts worth 35 per cent to social services which, as she points out, suggests that the services which disabled people rely on are being targeted by the council to make further local savings.

"It's a complete and absolute disaster. If it isn't replaced like for like it'll take the lives of disabled people back to the days when nobody had any support and you ended up in a Leonard Cheshire home."

Maria Miller says that safeguarding the position of existing recipients of the ILF is a priority.

Following the publication of a report into the funding of the social care system later this year, the Government will carry out a formal consultation, which will inform decisions on determining how best to continue to support existing users of the ILF into a social care system based on the principles of personalised budgets.

mediawatch

Boyle in hot water after gags

It's a feat not even managed by Bernard Manning: a comedian being on the radar of both the equality watchdog and broadcast regulator. **Paul Carter** reports



Comedian Frankie Boyle has come in for renewed criticism from disability groups following a series of controversial jokes and sketches featured on his late night Channel 4 show, *Tramadol Nights*.

The Scotsman sparked outrage in the media after making comments about Harvey Price, the disabled son of model and television personality Katie Price, also known as Jordan.

Boyle said: "Jordan and Peter Andre are still fighting each other over custody of Harvey. Eventually one will lose and will have to keep him."

He then went on to make a remark that implied Harvey would have to be restrained from sexually assaulting his mother.

Miss Price has since complained to the broadcast regulator Ofcom over the issue, who has said it will investigate whether there has been any breach of the broadcasting code.

Mike Smith, Chair of the Disability Committee of the Equality and Human Rights Commission (EHRC) said that Boyle's attitude

towards disability highlights a wider problem.

In a statement on the EHRC's website, he said: "The jokes about Harvey are distasteful enough, but it surprises me that people are not also talking about the many other jokes and sketches in the programme that relate to disability. These are not worth repeating verbatim, but to give you an idea of the material, Mr Boyle also takes offensive, stereotyped pot-shots at wheelchair-users, people with mental health conditions, Stephen Hawking's disability and cancer victim Jade Goody.

"I have been to comedy shows where disabled comedians have made jokes about disability, and they have been really funny. More importantly, they have been empowering and have challenged stereotypes.

"But Mr Boyle's disability-related jokes are different. My concern is not just that his jokes are distasteful or hurtful to individuals (and in Harvey's case, someone not in a position to stand up for themselves). They denigrate disabled people in a way that implies that they are

not real humans, and they are to be ridiculed or feared. As a consequence, this kind of humour perpetuates the discrimination and bad attitudes that many disabled people face."

He says that the EHRC's work into researching disability hate crime has found that in many instances, perpetrators of such crimes have been found not to view their victims as human beings with the same human rights as non-disabled people.

Jokes such as Boyle's reinforce that view, he says. However, Smith feels that

the media outcry and extensive coverage may ultimately prove beneficial for disabled people, as it forces the public to confront the issues around disability and challenge difficult views.

"From my perspective controversies such as this actually help our cause," he says.

"Not that long ago, disability-related prejudice directed at the TV presenter Carie Burnell created public outcry. The reaction to Mr Boyle's performance indicates that people find these kinds of attitudes

unacceptable. Both these incidents speak volumes in terms of just how far we have to move, as a society, in the way that we value, respect and treat disabled people. This debate about what is and is not acceptable will encourage more people to examine their prejudices and hopefully provide stimulus for change."

Meanwhile, mental health charity Rethink has also submitted a formal complaint to Ofcom over a sketch on *Tramadol Nights* that parodied attempts to tackle stigma around mental

illness by mocking an advert produced by the Time to Change anti-stigma project, run by Rethink and Mind.

Stuart Baker-Brown, who appeared in the original TTC advert said: "Stigma and discrimination can be just as harmful as the destructive symptoms of mental illness itself and this sketch can do nothing but cause further harm. It is a shame Frankie Boyle has to act in such an insensitive and unintelligent manner towards those who suffer deeply and towards those who are far less fortunate than himself."

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politics

Begg honoured for services to disabled people

In the Queen's New Year Honours List, the disabled MP Anne Begg was made a Dame. As **Ian Macrae** discovers, she sees this as very much a part of her continuing parliamentary journey

In the past, when disabled MPs – David Blunkett for one – were asked why they didn't do more for disabled people, the stock response was along the lines of "I didn't come into politics to represent just a part of the community..." etc.

Anne Begg (*pictured, right*), Dame Anne Begg as we must now call her, admits that this was very much how she used to think.

"I started off with that attitude as well, because you have to establish your own identity and I was keen not to be known as 'the disabled MP'. But things changed.

"I started to get more interested in social security and it was that that made me take more interest in disability.

"When I got elected I knew no more about disability benefits than anyone else. Then there were some changes to Incapacity Benefit and journalists phoned me and asked me what I thought about it and I said it wasn't something I was interested in. They said, 'but it's a disability benefit'. And I



said, 'but IB is an unemployment benefit for disabled people and I've never been unemployed.'

"But once you start looking at a subject, you get more interested in it and that's why, since 2001, I've been on the Work and Pensions Select Committee."

Such was the blossoming of her interest that, since

May 2010, she's been Chair of that Committee.

It's a role that requires her to be rather more restrained, more reticent even, than perhaps she might otherwise be.

For example, this former teacher didn't feel it appropriate to give marks out of ten for the performances of individual

government ministers.

She's willing, though, to address the Coalition's welfare reform and its impact in wider terms.

"In some cases there are things we can welcome in principle, but of course the devil is always in the detail. So obviously, Universal Credit is the holy grail of welfare reform but until we

know what the levels are, and how it will affect individuals, it's impossible to say whether it's a good or a bad thing in and of itself."

Putting it another way, she recognises that a simplified benefits system might well be a good thing, but not if it pays people less money.

She also sees a deeper and fundamental problem with the Government's current agenda.

"The rhetoric is that we want to help people back into work, and that's absolutely correct. But then some decisions come right

out of the blue.

"So, for instance, Maria Miller says that the benefits system should be much more personalised so that people have and manage their own budgets.

"And then she cuts Disability Living Allowance Mobility Component to residential care home residents when that's the epitome of personalised budgets."

Similarly, Dame Anne regards the closure of the Independent Living Fund (see "Disability Rights", p.15) as, "another example of the actions and the rhetoric not marrying".

Much of what she says is on familiar territory for readers of *Disability Now*. The "medicalisation" of DLA, for instance, flies in the face of much that she's championed.

"I've fought very hard over the years to get disability away from health, saying that it's not a health issue, it's a human rights issue.

"I saw something on Twitter recently, saying that disability benefits should be

a matter for the health departments. That to me would be completely retrograde."

Her immediate priority as Select Committee Chair is the chance to question Secretary of State Iain Duncan Smith at a session in the near future.

So the Committee has been asking people for submissions giving their views on Universal Credit. "That, of course, is very much his baby."

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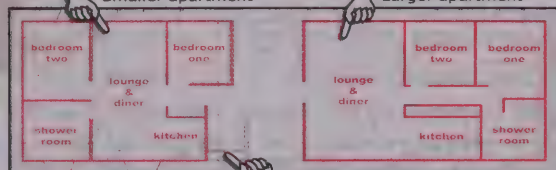
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Ireland's toothless Celtic tiger



As a blind person growing up in Ireland, **Martin Conway** went through the mainstream education system. He has also run his own business and is now a county councillor. Here he talks about the parlous state of disability politics among our nearest neighbours

The total population of Ireland is around four million. The standard figure given in terms of numbers of disabled people is around five per cent. That means there are around 250,000 of us.

Until recently most of the population lived in rural areas, but now it's more like 50 per cent living in urban areas and the other 50 per cent living in small towns and the country.

Anti-discrimination

legislation here is not as strong as in somewhere like the United States. There's been a lot of difficulty in getting legislation which is acceptable both to the communities representing disabled people and the

Government. There was a genuine attempt made a few years ago, but that fell on its face largely because agreement couldn't be reached among the various disability groups. So there's nothing like the Disability

Discrimination Act in the UK.

The main problem is that the lobby in Ireland is very fragmented. Unfortunately you have a significant number of advocacy groups representing a whole spectrum of disabilities and you also have the service providers, groups which were set up because they wanted to do good work.

It's estimated that in Ireland we have around 600 groups representing disabled people. 200 of those would be service providers and they're scattered all over Ireland. They're given funding because basically they're doing work which should be done by the Government.

You also have 400 groups involved in advocacy. A lot of them also receive state support, but that's part of the problem.

We need a much more streamlined advocacy and representative sector in this country. There's a lot of competition among the existing groups for funding, for members and in terms of wanting to exert influence. So they're competing with each other instead of working together.

There's a lot of tension among disabled people in this country anyway. That's meant that further splinter groups have been set up. That then empowers other people to have more of an

influence on policy. A lot of those 400 organisations would have chief executives and other paid staff and not all of those chief executives and staff are themselves disabled people. So there are, in my view, people who have made a career out of disability without having any sort of disability themselves.

Irish people are quite political and disabled Irish people are quite political as

There's a lot of competition among the existing groups for funding, for members and in terms of wanting to exert influence. So they're competing with each other instead of working together

well. But so far, we've lacked a leader who earned or pulled in the respect of disabled people.

One thing which we need to help tackle this problem is government leadership, for them to say, 'Listen, we're not providing funding for 600 organisations, you need to come together, have some sort of a forum and just reduce the numbers'.

There's a billion Euros a year made available to

NGOs in the disability sector. That's a significant amount of money, but you can see how much of it goes on administration instead of helping service users and doing real advocacy work.

I believed in my younger days that leaders would emerge from those bodies who would affect change. That didn't happen. The reason that it didn't happen, certainly in the last 15 years, is that the Government threw money at every problem because they had lots of it. Probably the reason the Government treated it as just another issue is that there wasn't anyone with a disability elected to public office.

That's where I come in. I'm the only county councillor, the only local authority member in Ireland who is disabled. I'm now seeking to run for the national parliament. My party is almost inevitably going to be the leading party in the next parliament. When that happens, and if I'm elected to the Dáil, I would hope to major on the disability issue. I think then that it would be incumbent on me to take a leadership role in sorting out what I call the disability myths in Ireland, ensuring that disabled people's voices are heard and that proper structures

are put in place and money is put to best use.

While there is the makings of a disability movement in Ireland, it's not as effective as it could be and it's certainly not as effective as it should be. There are some good people within the movement, very well motivated, very bright, but again they're splintered and fragmented all over the place and that is reducing their effectiveness.

With respect to how disabled people are viewed by the rest of the population, it's come a long way. There is an acceptance now. Ireland previously had a very catholic ethos where disabled people were seen as needing to be minded and pitied. Now we've moved almost full circle and we're very much a secular society where people are respected in their own right. We're a far more educated society and that has brought a new common thread of attitudes.

The Celtic tiger years certainly opened up opportunities for disabled people to show that we could do jobs, but now, with unemployment running at ten per cent, the problem isn't persuading people to employ us, it's about a lack of job availability.

• Martin Conway was talking to Ian Macrae.

one2watch



The tribes of Jacob

Fresh from triumphant performances in the play *Tribes* at London's Royal Court, and with rave reviews for his scrap book, **Jacob Casselden** (pictured left) is confident that the hearing world could now be his oyster. In answering our ten questions, he reveals more hidden talents than most and an unexplained hatred of traffic lights.

What excited you about *Tribes*?

Everything! It's a beautiful and clever play, written by Nina Raine, and something that's never been done before. It opens doors on issues of deaf identity, communication barriers and so on!

Other than Deafness, do you have anything in common with the character you play?

The fact is, anyone who's deaf, born and raised in a deaf family is bound to have experienced difficulties with the hearing world, especially with schooling. It can be tough for those who are deaf, trying to survive the mainstream hearing schools. But this motivated me to achieve and grow stronger for the real world.

What do you like most about acting?

I come from a very musical and deaf family. I love acting. I love exploring lives, emotions, leading different lives, and testing my skills on stage.

What do you like least about it?

Rather strange question. What do I dislike about acting? Sure we have long hours, lots of lines to learn, movements, researching the era, characters, backgrounds. But isn't that supposed to be the fun part?

How do casting directors react to your Deafness?

It's as though I am either royalty or a rather strange being from Mars! There's still work to be done and I feel there will be more strange reactions to come when I audition for work based on hearing characters. But then again, this is a challenge.

What makes you angry?

Right now? Traffic lights...

If you were Prime Minister, what would you do to improve things for Deaf and disabled people?

I would make British sign language a GCSE subject. French, German and Italian are useful languages to learn. However, why not the language for those who live closer and happen to be deaf!

Who's your favourite Deaf or disabled person ever?

Liz Crow, a superb film director and writer, an intelligent woman who strives to open up the forgotten treatment of disabled and deaf people by the Nazis. I am always in awe of Liz's work.

How would you sum yourself up in ten words or less?

Haha this is hard! Hmm... An hour later the lines I created sound really pathetic, so I will keep them to myself – sorry!

Do you have any special or hidden talents?

I am a drummer, tap dancer, monologue reciter and sign singer, and a very keen rugby player! Hidden talents... I was told I'm a bloody good flirt... Does this count?

→ Who do you think is One to Watch?

Send us your nominations for likely lads and lasses who could answer our 10 questions. They can be rising stars in any field of entertainment, business, the media or beyond

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Jody McIntyre quickly became the public face of resistance during recent student protests after video footage emerged that appeared to show him being dragged from his wheelchair by police. In an uncompromising and unflinching interview he gives **Paul Carter** his views on the incident that made him an overnight celebrity, and how he feels disabled people should come together to fight the Government's cuts agenda

When images from the student protests taking place in London and across the country were being splashed all over our television screens in December, it seemed

entirely plausible that another Winter of Discontent may have been on the horizon, spurred on by a new generation of politicised young people. Claims and counter-claims of violence from police and protestors

spread across the airwaves.

However, amongst all the tales of kettling and kicking royal cars, one story soon began to surface that captured people's attention. Rumours began to spread that during the



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protest a disabled person had been pulled from his wheelchair by the police, and dragged across the street. In less than an hour after news of the alleged incident broke, a video appeared online, that appeared to show police dragging a man, surrounded by outraged and incredulous eyewitnesses.

Footage of the incident soon became viral, and spread quickly across video sharing sites such as YouTube long before the mainstream

press picked up the story, largely thanks to social media outlets such as Facebook and particularly Twitter, where thousands of users reposted links to the video.

Soon, the person in the video was identified, and a name began to circulate. It was Jody McIntyre.

Despite being only 20 years old, Jody is no stranger to protest, and is already something of a seasoned political and social activist, campaigning for equality for disabled

people as well as supporting a number of other causes, such as the fight against tuition fee increases which so unexpectedly thrust him into the wider media spotlight.

In December's *Disability Now*, he wrote in World View about his experiences as a disabled person living for nine months in Palestine, of which he has been a vociferous supporter since childhood.

For many people, disabled or not, getting caught up in such a high-profile media storm would be overwhelming. Jody, however, remains remarkably matter of fact, and says that in his opinion, the incident was almost to be expected from the police, about whom he has frank and forthright opinions.

"People shouldn't be surprised by the police pulling someone out of a wheelchair more than say a policeman smashing a non-disabled person over the head with a truncheon," he says.

"This is the police's role in demonstrations – to provoke and initiate violence and to suppress any demonstrations that look like they're going to be effective. Essentially that's their aim. If it's ineffective protest that isn't making any difference then they don't need to do anything. If it's becoming effective in any way then they have to suppress it.

"Obviously I didn't quite expect it to be as big a story as it was, but I can kind of understand why because it's obviously quite shocking to see an institution that you've been told is here to protect us – that's what you've been told all your life – not only not protecting us but pulling disabled people out of wheelchairs. It really turns the tables on everything they teach in school about the police. You don't see that on *The Bill*."

Jody has lodged a formal complaint →

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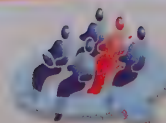
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to the Independent Police Complaints Commission, and says he is still in discussions with a lawyer as to the best course of any potential action.

The alleged incident seemed to capture the public mood, and soon people began to ask why mainstream news outlets had yet to pick up the story. When they eventually did, Jody again found himself at the centre of a storm, this time with the BBC following a live on-air interview with *News 24* presenter Ben Brown.

The interview resulted in 420 complaints to the broadcasting regulator Ofcom, from people claiming that the line of questioning adopted was overly aggressive and inappropriate. Meanwhile, the BBC itself said it had received what it called a “considerable number of complaints” – believed to be in the thousands.

Kevin Bakhurst, Controller of the BBC News channel, later defended the interview with Jody, stating: “I have reviewed the interview a few times and I would suggest that we interviewed Mr McIntyre in the same way that we would have questioned any other interviewee in the same circumstances: it was quite a long interview and Mr McIntyre was given several minutes of airtime to make

a range of points, which he did forcefully; Ben challenged him politely but robustly on his assertions.

“Mr McIntyre says during the interview that ‘personally he sees himself equal to anyone else’ and we interviewed Mr McIntyre as we would interview anyone else in his position.”

He was asking me these questions while a video was playing on the screen of a policeman pulling me out of my wheelchair, and he's asking me ‘were you throwing missiles?’

Perhaps unsurprisingly, Jody sees things differently.

“He [Ben Brown] knew I hadn’t done anything wrong,” he says.

“He knew that I didn’t deserve the treatment I got, so he just kept asking me ‘were you throwing things at the police?’ I already answered him when he asked me the first time, he didn’t need to keep asking me.

“He was asking me these questions while a video was playing on the screen of a policeman pulling me out of my wheelchair, and he’s asking me

‘were you throwing missiles?’

“I know they got a huge number of complaints. I saw there was something on their website saying ‘we don’t think we did anything wrong’. I don’t mind. I’ll still talk to them, you just have to know what you’re coming against. If you’re aware of the role of these institutions, it’s not so much of a shock when they say ‘were you rolling your wheelchair towards the police?’ The funny thing about that question is that I don’t understand the implication. If someone rolls towards a policeman in a wheelchair, the police can just pull you out and drag you across the floor? For rolling towards them? I mean, come on.”

When conversation turns to the wider discussion about the impact on disabled people of the current political climate, it becomes even clearer that Jody is committed to direct action, and to making people take to the streets to get their voices heard.

He says that far from being put off by what he says happened to him during the student protests, other disabled people should be inspired by his experiences to take action themselves.

He says: “There are a few different ways of looking at it. One, you could say the police will be more nervous now of ➔

pulling people out of wheelchairs. Two, you could say that the public in general supported me so they'll support you as well if it happens to you, but also the main thing is that we can't be bullied by the actions of the police into inaction. We can't be covered into silence by the rhetoric of the Government. We have to keep fighting, and nothing should put us off. Even if they sent the army into a demonstration, nothing should put us off because if we keep fighting, we will win."

Around Easter this year, trade union organised marches are expected to take place in which groups of people from across society – including disabled people – are likely to play a role.

Jody argues that such combined protest is much more likely to succeed than if disabled people opt to

If it's ineffective protest that isn't making any difference then they don't need to do anything. If it's becoming effective in any way then they have to suppress it

campaign and protest separately.

"To be honest, everyone needs to mobilise, disabled people and non-disabled people. But obviously, disabled people are going to be amongst the hardest hit.

"There's no point in being disparate groups, everyone's going to suffer from the same thing, so there's no point in saying this is about this group of people or that group of people;

everyone can fight together."

So, is he happy to be seen as a figurehead for the disability protest movement?

"I'm not seeking attention or seeking any role. Any way I can be useful, if me just going to demonstrations helps the cause, then I'll go to demonstrations. If merely talking to the media helps the cause, I'll do that. Everyone has to do whatever they can, it's not really a matter of one person being more important than another person. We all have a role to play."

While some of his political views may be likely to polarise opinion, his desire and commitment to pushing for social change cannot be questioned. With that in mind, it seems unlikely that we've seen, or indeed heard, the last of Jody McIntyre. ■

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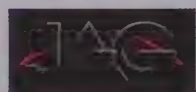
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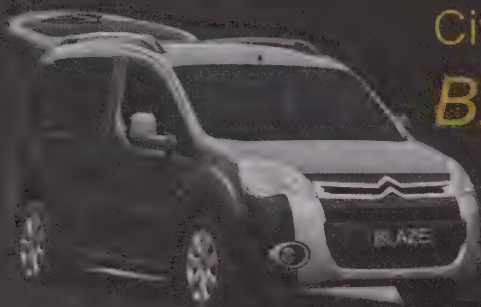


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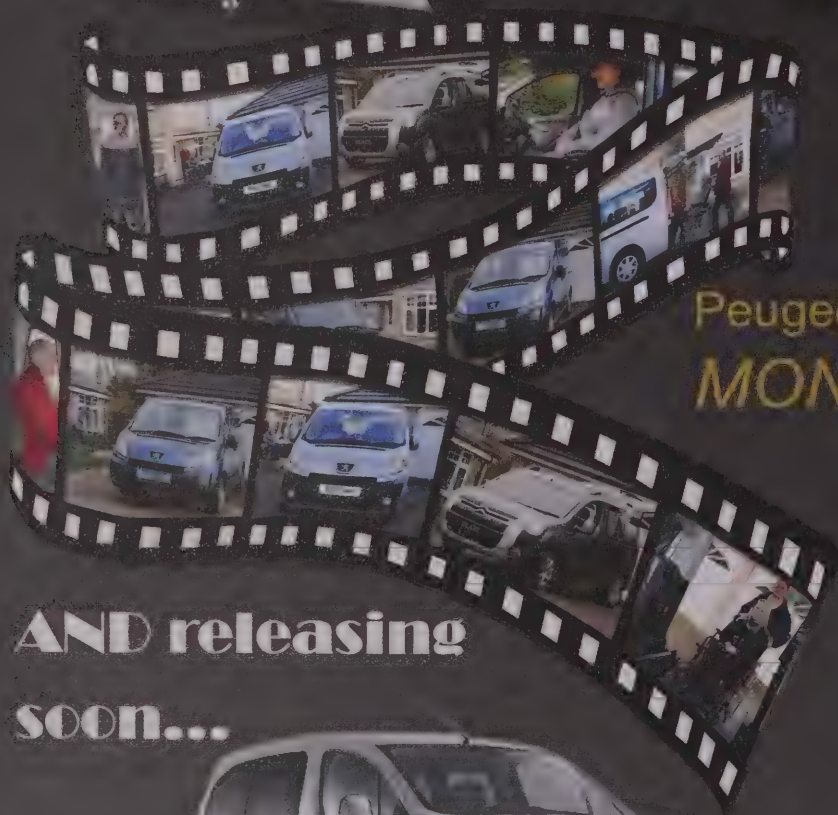
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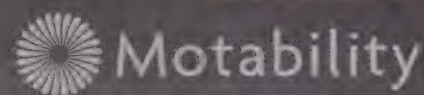
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Hard choices – birth and termination

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Three disabled women tell **Annie Makoff** about how they made and lived with their choices

In October last year, a Bedfordshire hospital hit the headlines in a six figure payout after they failed to pick up a spina bifida diagnosis in an antenatal scan. The mother of the disabled boy told the court that had she known, she would have undergone a termination. It is all too easy to condemn her comments. Indeed, the case raises a lot of questions, not least how will this child feel about his mother's comments when he is old enough to understand? It also raises ethical questions: is it "right" to have a termination following a prenatal diagnosis? Yet, as experience tells us,

it is never quite as clear-cut as "right" or "wrong".

Under current law, a termination can be carried out no later than 24 weeks, unless a "severe handicap" has been diagnosed, in which case, a termination can be carried out right up until full term.

This may seem unethical on the surface, but there are those who argue that taking various factors into consideration (the mother's situation, the difficult decision the parents face, the time for second or third opinions) it can give women the time and space to make an informed choice that is

right for them, their unborn child and their families.

But there are also those who say that doctors and other NHS professionals are too ready to rush to judgement and offer terminations, even pressurize mothers with an antenatal prognosis of disability into ending their pregnancy.

Demonstrating just how unhelpful it is to make judgements as to the rights and wrongs of termination, three women spoke to *Disability Now* about the difficult decisions they had to make following an in utero diagnosis.



ELENA'S STORY

When I became pregnant at just over 40, my husband and I knew there could be a risk with the pregnancy. Neither of us felt that we lived in a world into which we could bring a disabled child comfortably.

I've worked with people with learning disabilities since 1985 and I've worked in care management and disability teams, but I had to stop recently because of the pressure I felt from emotional trauma. My clients were often refused vital services and support that they desperately needed and I found it very difficult seeing this denied to them. I experienced first-hand the distress some carers felt who weren't coping and the guilt they felt because of this.

I couldn't bear to bring my precious



SUPRIJONO SUHARJOTO

When we received the diagnosis of Down's syndrome, it felt like a death knell. I thought 'so that's it' and I cried and wept

daughter into this awful world where the services are nil. So when we got the diagnosis of Down's syndrome, it felt like a death knell. I thought "so that's it" and I cried and wept.

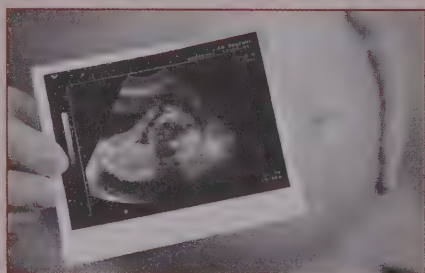
I know our decision will be countered by people who don't agree

with what we did, but because of what I'd been through as an employee, the thought that I may have to deal with services like that in the future – that my daughter may suffer – was horrific. So, following counselling, we decided to go ahead with the termination.

At that point, we didn't think we had much time. We didn't know then that we could have delayed things – we could have had further tests and taken longer to make our decision. But even so, I don't regret anything. I miss her, but I don't regret it.

I gave birth to Jessica a few days after the termination procedure which happened at 18 weeks.

Strangely, it felt very peaceful. I still look at the pictures we took of her, and look at her beautiful face. She's my baby girl and I love her.



MIROSLAV BENEDA

JULIE'S STORY

I'd already decided that I didn't want a formal scan to test for Down's syndrome. If my unborn child had a disability, I'd deal with it – I knew it wouldn't make any difference to me. Despite my feelings, the hospital performed one anyway. They noticed Theodore had fluid on his lungs which is symptomatic of Down's syndrome.

From that moment I was treated as a leper. I was put into a side room by myself that had leaflets about bereavement and termination. They

left me by myself for several hours. I wasn't even allowed to sit near the other mothers – they thought it would be too upsetting for them. Eventually I saw the consultant who was adamant that I should have the termination immediately. I burst into tears. I told him I wanted to go ahead with the pregnancy. He said, "he'll have no life".

I had to go back every six weeks to see this consultant and every time, he'd say, "have you thought any more about a termination?" I was under tremendous pressure – it felt like brainwashing. I was a single, older mother, therefore I was wrong to even consider going ahead with the pregnancy. But I knew a termination wouldn't have been right for me, I wouldn't have lived with myself. I was told that my son had less than 50 per cent chance of surviving past 24 hours as I had to have an emergency

I saw the consultant who was adamant that I should have the termination immediately. I burst into tears. I told him I wanted to go ahead with the pregnancy. He said, 'he'll have no life'

Caesarean at 35 weeks. But he's a strong lad and he pulled through – he's two years and nine months now.

I felt very isolated during and after the pregnancy – we never really had the support – even our health visitor told me I had to move as the area wasn't suitable for a child with a disability. But I found a lot of support from online forums. So yes, it's been hard at times, but you get there. And I wouldn't change Theodore for the world.

ANDREA'S STORY

Jack wasn't unwanted. I would have given anything to keep him. I didn't want a perfect baby, I just wanted a baby that wasn't going to be in pain from the moment he was born. But we were told at our 20 week scan that Jack had osteogenesis imperfecta – a severe brittle bone disease. A second opinion told us that Jack might survive but it would be touch and go. They went through a list of what would be wrong with Jack and the problems he would have.

My husband and I agonised for weeks about what would be the best for Jack, but we knew that interrupting the pregnancy meant I could save him from future pain.

I carried Jack for an extra five weeks because I didn't want to lose my baby. Every scan showed that Jack had more broken bones. If we did go ahead with the pregnancy and he survived birth, he probably wasn't going to leave hospital and would eventually break every bone in his short life.

We decided to interrupt my pregnancy at 26 weeks and 4 days. The consultant inserted a needle through my stomach and into Jack's heart. I lay there for an hour while she tried to stop Jack's heart. I went into induced labour on the Thursday and Jack was born in the early hours of Saturday morning.



“Every scan showed that Jack had more broken bones. If we did go ahead with the pregnancy and he survived birth, he probably wasn't going to leave hospital and would eventually break every bone in his short life”

We spent time with him afterwards. We had him blessed and the nurses dressed him in the little

outfit we'd given him. My family visited and we took pictures. Eventually the nurse advised us to let him go because he was changing and his skin was tearing from where we were holding him.

We hadn't realised there were exceptions to the termination law – but we were the exception because of the severity of Jack's condition. I am grateful we had that time – I would have given anything to stop Jack's pain. He'd already suffered enough. We are going to miss him forever: he will always be our first-born baby boy. ■

• Some names have been changed.

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yourviews

Who's fighting the benefits scrap?

I'm very, very worried about all I'm hearing about the Government's plans to scrap all our benefits and amalgamate them into one.

I have severe epilepsy and have been unable to work since I started having three or more tonic-clonic seizures a week. I'm starting to get very depressed as I'm pretty sure my family would

collapse under the financial burden of carrying me.

My wife is already working all the hours she can, to try to pay the mortgage and our bills, and feed the kids.

Amalgamation will finish us, I'm sure. Is anyone doing anything? Is anyone fighting? What is happening? Can I do anything?

Martin Thorn, by email

Accessible transport has 'come a long way': let's not lose it

I'm writing with reference to the letter from Will Bee (*Disability Now*, November 2010) about access to buses.

I must have missed the negative fallout from Emma Bowler's article ("On the buses", *Disability Now*, July 2010) but I, too, am worried that the campaigning and sheer hard work done by disabled people over the years could be jeopardized by a lack of perspective.

Will is right in saying that some disabled people still lack access to bus transportation in rural areas, but we have come a long, long way and we must not lose these gains.

I'm a wheelchair-user and my life was transformed when buses became accessible. I now use buses every day and I'm more confident in travelling on

them than ever.

One reason why some disabled and older people don't use buses is that they may never have been on one or, if a trauma has occurred, they may have lost their confidence.

We need people who are willing to support people in learning to get on and off buses. People who currently rely on local authority vehicles and ambulances could use public transport if they were helped to regain their confidence. This would open up their lives in many important ways and provide people with more options than just local day centre attendance or hospital visits.

Accessible public transport must be assured.

Ann Macfarlane, Surbiton, Surrey

Why can't local authorities recognise best options for autism?

My journey began in April 1994 when my beautiful baby boy Steven was born, while I was living in Dubai.

Autism wasn't a concern of mine when he was born, but its diagnosis two-and-a-half years later brought

my life to a stop.

At the time, there weren't many schools in Dubai that were prepared to take an autistic child, and information and support on the subject was negligible.

Instead, I taught him at





CABY KOOLJMAN / STOCKLIB

home until he was six years old. During that time I worked hard to understand what goes on in his brain.

Seeing the amount of progress he was making in Dubai, I convinced myself that my son would make even greater strides if I were to return home to the UK, where facilities are better.

I returned to the UK in July 2000, and accepted a place for Steven in an autistic school run by the local education authority (LEA).

Within no time I saw that Steven's needs were being

ignored and that he was regressing in every skill that I had previously taught him. This was difficult for me, because the school and the education authority ignored my reactions to what I saw.

After a year, I withdrew him from school and started teaching him at home again, hiring and training psychology students to work with him. During this time he again made progress in leaps and bounds, which told me that this was the type of support he needed.

At this point I took the education authority to

tribunal, in an attempt to get funding for Steven to be taught at home. Although home teaching was my preferred choice, I knew that the LEA could have argued against it, as I didn't have space and had a toddler to care for as well, so I offered the LEA two choices: one was to fund a home programme and the other was to fund an autistic school of my choice.

After causing me more stress, the LEA eventually opted to fund an ABA school (Applied Behaviour Analysis is a method of teaching used for autistic children) where again Steven made no progress.

When Steven reached secondary school age, the LEA suggested another autistic school. By this time I didn't have a lot of choice and agreed to the school it proposed. I was also suffering health issues at the time and decided I couldn't keep battling to teach Steven at home while also dealing with other demands. Not until he became 16, after I'd moved to a larger home with more space, was I able to teach him myself again.

These experiences

prompted me to write a book, called *No Matter What*, in an effort to help myself cope and make others aware of the challenges of autism.

The core of the story is that the LEA wasted resources keeping my son in what I felt were more like childminding services than educational institutions. Funds could have been used more efficiently if Steven's needs had been properly evaluated.

Now, after all these years, I see that the LEA didn't only waste its resources but wasted eight years of Steven's life and left me to pick up the pieces.

Because of the LEA's behaviour, I had to start re-teaching my son when he got to the age of 16, when the challenges were far greater than they would have been if they had been addressed properly eight years earlier.

My experience has led me to become an advocate to support other families with autism, because I've learnt that my son's case isn't an individual one. There are thousands of examples of UK families being failed by the system.

Sandy Howarth, London

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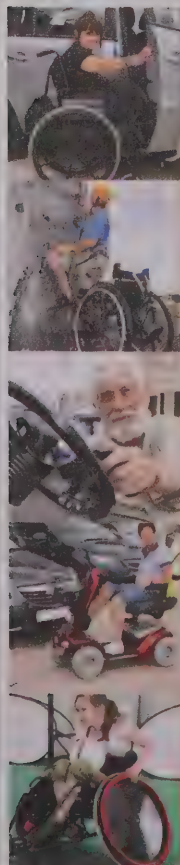
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Stopping care funding lottery

If the coalition Government wants to be true to its stated commitments to “localism”, “fairness”, “the Big Society”, then, says **Andy Rickell**, it needs to reform adult social care by removing the responsibility for allocating its funding from local authorities

On 23 October, just after the spending review, David Cameron was quoted as saying: “What’s more we’ve chosen to protect the services that families rely on, like the health service, schools and social care.” Indeed the spending review actually added money to the allocated social care pot. But now we’re at the point in the year when local authorities set their budgets, and we can expect to see major social care cuts.

Why? Because social care funding is not decided by Westminster government. Instead lots of local authorities make those decisions – choosing between social care and potholes in the road, or libraries, or education, or recycling. Central and local government will blame each other – like a pair of twin Pontius Pilates washing their own hands and denying responsibility for the social care cuts or the hikes in charges, leaving disabled and older people

This approach to funding originates from a model which assumes social care should be delivered collectively. But direct payments and individual budgets mean social care can now be individual and personalised

unable to hold anyone to account.

This charade, which results in opaque postcode lottery entitlements, uncertain and unfair charging costs and an inability to take a known social care package with you if you want or need to move, has to stop. This approach to funding originates from a model which assumes social care should be delivered collectively. But direct payments and individual budgets mean social care can now be individual and personalised. This true “localism” empowers

the individual directly – the local authority is no longer needed as a middleman. A local bureaucrat is no more accountable than a central one, but having a local one too just adds cost and allows responsibility to be avoided. Indeed one council leader admitted that they spend £1 in every £3 of social care money deciding what to spend the other £2 on! Enough of wasting money that disabled and older people could be better using themselves.

Local authorities should have strategic responsibility for overseeing the flourishing of a local social care market – nothing more. An amount equal to the rest of current social care funding should be removed from council grants, and distributed by a central government department, based on a

nationally uniform transparent and supported assessment process that can be delivered locally via something like a Jobcentre equivalent. With intelligent use of people knowledgeable in the social care personalisation agenda – retrained social workers etc – this can be a much more efficient process, empowering disabled and older people with the money they are entitled to directly. And it offers real roles for the effective work of centres for independent living and other disabled people’s organisations.

Please can we make sure that the long-term reform of social care funding is about a fair and better system that empowers citizens, not just another “reform” exercise which only seems to care about reducing public funding.

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Is there a fliers' buddy system for disabled travellers?

Q I want to fly to Denmark alone but I'm wheelchair dependent. Various airline websites say I can't do this for safety reasons. Do you know of a flight buddy system for disabled travellers?

Belinda Bruton, by email



Andy Wright

says: Your question is a

good one, as an increasing number of single travellers wanting to travel are now being prevented on the grounds of "health and safety" or whatever excuse airlines can conjure up to prevent them from having to carry high maintenance passengers!

In view of that, your suggestion of a flight buddy system is a very good idea, and could well become more popular in the future if legislation continues in the same direction. The trouble is, I'm not aware of any such system at present.

You'd probably be best advised to contact an agency that provides carers to accompany holidaymakers. Try activeassistance.com and ask them if they could offer their services simply to accompany a passenger on a flight only.



TRAINMAN32 / SHUTTERSTOCK

Gathering winter fuel

Q I'm on incapacity benefit and DLA mobility and care components, but because I don't receive income support I don't qualify for winter fuel payment. That's really annoying because I'm a single disabled female living alone and it's tough paying bills and staying warm and keeping fed, whereas I know someone who's on income support and DLA and lives with his dad, and both he and his dad get the winter fuel payment. Can you tell me how that's fair and why I have to struggle?

Tracy Paddock, Caerffili



Disability Alliance's Ken Butler **says:**

From what you've said, I think the issue you raise relates to cold weather payments and

not winter fuel payments: the two are often confused.

Winter fuel payments are an annual lump sum paid automatically to all those who've reached pension credit qualifying age. For both men and women this is being steadily raised from 60 to 65 between 2010 and 2020, alongside the rise in women's state pension age.

Cold weather payments are different and are weekly payments of £25, paid to certain people when the average temperature recorded or forecast over seven consecutive days in their local area is zero degrees Celsius or less.

In this event, a weekly cold weather payment is made to people already receiving pension credit.

Other people can qualify if they receive income support (IS), income-based Jobseeker's Allowance (JSA) or income-related

Employment and Support Allowance (ESA) and are responsible for a child under the age of five; or are getting child tax credit that includes a disabled or severely disabled child element; or their IS, JSA, or ESA includes one of the disability or pensioner premiums; or their ESA includes the work-related support component.

As you can see, the "qualifying test" applied to cold weather payment eligibility relates solely to being paid one of the means-tested benefits listed.

All of this is on the basis that entitlement to cold weather payments should be means tested and that the best way of doing this is by limiting entitlement to those who meet the income and savings limit rules for being paid pension credit (i.e. IS, JSA, or ESA).

Unfortunately this results in people not qualifying for ESA, even if their contribution-based incapacity benefit is just a few pounds over the ESA income limit.

While you can no longer claim income support on grounds of incapacity for work, you should seek the advice of your local Citizens Advice Bureau or other local advice centre, to see if you are being paid the appropriate care component level of DLA and, in turn, if you may be entitled to ESA.

Must I let a letting agent inspect us?

Q I'm a full-time carer for my wife, who has multiple sclerosis (MS) and is in a wheelchair. We rent our home and the letting agents want to do an inspection.

My wife lives all her life in the downstairs lounge, either in her recliner or wheelchair, and intensely dislikes the idea of having any visitors in our home. She feels they invade her living space and personal privacy. She is therefore adamant that we do not have an inspection.

Apart from anything else, we have breakfast at 6am; by 9am (sometimes earlier) she's exhausted and wants to sleep. I don't want to upset my wife by allowing the agents to do an inspection while she's asleep. What should I do?

Name supplied



Kate Sheehan replies: Your wife has a complex condition

that you manage effectively between you. Change to the routine causes stress, especially on matters that might appear trivial. That said, you probably have a contractual duty to allow inspections.

When you signed your



RUSTYJAW / SHUTTERSTOCK

letting agreement, one of the contractual points would have been to allow the landlord or agent an annual inspection. This benefits both sides. It gives the owner the confidence that the tenant is maintaining the property properly and lets the tenant raise any issues that are deemed necessary.

I therefore suggest you try and compromise. Explain your wife's condition and anxieties to the agent, confirm a date and time that would suit your wife, ask if the inspection can

take no longer than 15-20 minutes, and suggest that any preamble is done on the phone prior to the visit.

I'm sure that if you try and work together to minimize the impact on your wife, the visit can be carried out quickly, without too much disruption.

Even if there's nothing in your contract, refusing a visit would not be viewed favourably by your landlord and might put your tenancy in jeopardy, which would damage your relationship. Compromise is always the best way forward.

→ If you have a question for our panel

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pete's place

Ignoring the scars of war



Injured ex-service personnel still have to rely heavily on charities for support and rehabilitation. **Peter White** asks why government offers such a raw deal

Few would deny that a civilised society has a duty to offer the best provision to those disabled in battle while fighting its wars. You might even say that such provision should be the standard for all disability, since how you acquired your disablement has no impact on how you have to deal with it.

The truth, though, is that government rhetoric has rarely matched this aim. In

our "land fit for heroes", disabled ex-servicemen used to have to sell matches on street corners to get by; and help tended to come from voluntary organisations like St. Dunstan's and the British Limbless Ex-servicemen's Association.

Relatives of soldiers shot for cowardice when suffering from shell-shock have been waiting almost a hundred years for an apology. If that's because

we now know more about this condition than we did then, explain the reluctance of the Ministry of Defence (MoD) to recognise post-traumatic stress disorder today, or the effects of chemicals on soldiers in the first Gulf War. Explain why servicemen who suffered hearing loss as a result of war injuries in the 1990s could only claim for initial deafness, not the incremental deafness that followed.

The MoD often fights to the last ditch to avoid paying more than minimal compensation. It may offer impressive rehabilitation

services in the immediate aftermath of injury to the rising number of servicemen wounded in Iraq and Afghanistan, but longer-term duties are often ignored.

The prosthetics offered to those who lose arms and legs may initially be "state of the art" but it can be a different story a couple of years later, when they go back for replacements. And too many people trained to fight at the limits of human endurance aren't helped to adjust to the different demands of civilian life.

Fostering a bond between all disabled people, however their disability was acquired, would help, because work done by and on behalf of ex-servicemen has often had wider benefits. Rehab work after the first and second world wars expanded society's view of the jobs we could all do; and the anger of disabled American soldiers returning from Vietnam led to the USA's groundbreaking anti-discrimination laws over access and employment.

Let's drop the idea that disabilities acquired in war are heroic and agree that all disabled people are united, that the best weapons for disabled people are their own tough thinking, and that there must be fair, appropriate provision by our still rich country, regardless of its banker-induced debts.

ed cetera



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guestcolumn

Knowing our own strength

A fierce but concealed political debate has been taking place about disability. This Government, (more so even than its predecessors) is determinedly challenging the nature and scale of disability in the UK. This issue has so far been presented in terms of welfare reform, but be clear that underpinning it are a whole set of hostile assumptions about disabled people.

The unstated message is twofold. First, we the Government don't believe that there are all these disabled people in the population. Numbers are inflated by a host of scroungers and fraudsters. Second, we will reduce these numbers by forcing people off support and disability and related benefits into employment, and by adopting methods for medically testing them that have more to do with our ideological objectives than with their health or impairment status.

It is notoriously difficult to calculate numbers of disabled people. But what we can say with some confidence is that the



As definitions of disability become wider and more inclusive, **Professor Peter Beresford** argues that an increase in numbers should turn us from an easy target for cuts into a powerful lobby

number of people with impairments – physical, sensory, intellectual – or related to mental health problems and other long term and end of life conditions, is large and rising. It is rising because of improvements in the survivability of infants and other people with impairments into older age, and because of the significant increase in older and very old people, the groups acknowledged to include the largest number of disabled people, it's likely that anything from a quarter to a third of the population are disabled.

So when politicians, like the current Coalition cabinet, pick on disabled people as a powerless and unimportant constituency, the reality is that it's going to be more and more difficult for them to maintain the discriminatory mindset that disabled people are a marginal minority that can't hit back. They are going to have to

recognise the diversity of disabled people. There are going to be more and more of us around. Who knows, we may end up being the majority. Now there's food for thought!

But it is not only reactionary and disablist politicians who must internalize this reality. We must too as disabled people. We are a very large interest group and we have to see ourselves much more as such. It was the vital legacy of the disabled people's movement that it set us on this road. Now, perhaps, at a time of an appalling increase in political oppression and discrimination, it's time for us to renew our thinking and determination about this.

It's a reminder that we need to regain our

What we can say with some confidence is that the number of people with impairments – physical, sensory, intellectual – or related to mental health problems and other long term and end of life conditions, is large and rising

confidence as a group and as a movement. But, also, it is a reminder to government that they will need to think again if they decide to attack us and our rights and needs. The Condem coalition needs to remember that when it takes us on, it is now almost certainly taking on many households, most families and every street. We only have to remember that we have the growing power of numbers to change politics.

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upclose&personal

Facing fears for the future

Louise Bretland-Treharne finds herself dealing with a condition which many healthcare professionals don't even recognise. And she's now also facing a future made frightening to her by Government welfare reforms

Schizoaffective disorder is the diagnosis given to someone who experiences both the symptoms of a mood disorder like depression, and symptoms of the type experienced with schizophrenia at the same time, or within days of each other.

Due to the symptoms often being similar to either schizophrenia or manic-depression, it is often seen as a controversial diagnosis. Some clinicians do not believe there are sufficient differences to justify giving a separate diagnosis.

In the early 1990s I was diagnosed with this disorder. I find living with this complex illness frustrating and distressing, even with the recognition that I manage my condition well.

Professionals say it is not the actual diagnosis that is important, but the effect of, and the way I manage my illness. On a superficial level, I find this concept helpful, but in reality it is not always applicable. Insurance companies, benefit forms et cetera require an accurate



The Government is now putting all disabled people under pressure, especially with interviews to evaluate and validate claims and health status of benefit recipients

diagnosis – an actual label.

When I was a psychiatric student nurse from 1990-1992, I did not come across this condition. I know you cannot confirm a mental illness as easily as taking an x-ray for a physical condition. I was originally diagnosed with manic depression, and later schizoaffective disorder. Will

I see a different consultant in the future and be given yet another different diagnosis? It is a scary, insecure position to be in.

Input from my community psychiatric nurse and psychotherapist is definitely helpful – even essential. I still suffer episodes of psychosis, mood fluctuations, sleep deprivation, eating issues, memory/concentration problems, difficulty in assimilating new information, conflict/confusion, suicidal thoughts and resultant loss of self-confidence and esteem. Some professionals do not recognise or understand the day-to-day challenges I face.

The Government is now

putting all disabled people under pressure, especially with interviews to evaluate and validate claims and health status of benefit recipients.

I sometimes feel suicidal because of the stress of my illness, but I have not actually tried to kill myself since 2001. Being called for interviews, or treated like a benefit thief could be too much. Surely professionals regularly assessing and therapeutically supporting me, and significant others, can be allowed to represent me and put my case forward to benefit assessors. I dread being thought of as a benefit-scrourning fraud.

But I am determined to utilise all opportunities, using my own life experience, Buddhist practice, and input from professionals. I aim to continue managing my mental health issues. Valuing all my strengths and qualities, I feel is essential, even if at times a tall order. My weaker areas I try to respect and nurture. I would like to one day be in a position to inspire and motivate others to find the courage to heal.

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A kind of dating

What's not available online. Food, booze, books, clothes: all there at the click of a mouse. Even love or lust. The internet overcomes many access issues for disabled people but, asks **Lara Masters**, does it also help level the playing field when it comes to cyber-courting?



Lara and her other half, together offline

For research purposes, and much to the chagrin of my OH, I signed up to Match.com and a site aimed at disabled folks called Dating4disabled.com, where people can search for a devotee or for a partner with a specific disability from a comprehensive list including "colour-blind" and "blind (one eye)"... Gulp!

I put up photos of me showing the wheelchair and on Match I got 150 "profile views" and 30 "winkers" (read that carefully) daily, but only 2-3 people per day bit the

cyber-bullet and emailed. On D4D from 60 "PVs" a day I received around 15 new emails – half of which were able-bodied suitors who avoided disclosing why they were on a disability-orientated site.

There were one or two guys on both sites that seemed bright, interesting and "attractive" so I asked a couple of disabled internet-dating aficionados what happens when you're genuinely looking for love. Or lust.

"John", 43, has tried Match, eharmony, Adultfriendfinder and Dating4disabled.

"On Match and eharmony I stated I used a manual wheelchair, but didn't post a picture displaying it. I found women older than me had less of an issue with it but those younger had often not read the description properly so were unaware of my disability!

"On AFF, a site based on sexual desires, conveying the idea that disabled people aren't 'A-sexual' – it merely requires more creativity – is difficult, and dating on D4D is also problematic because people sharing a common ID as disabled doesn't remove other biases. There's also the 'devotees' who want to date a disabled person due to a fetish or to 'take care' of them. I've experienced both kinds, and as someone opposed to help except in exceptional circumstances and wishing to promote equality, the experience was not pleasant.

"I've met 3 people on AB sites and acquired several friends via D4D but my 'success' rate isn't necessarily disability related – the eharmony compatibility test judged me incompatible with everyone on their books before the issue of physical appearance and thus disability even came up!

"Recently, I've met more valid relationship prospects on Badoo but I suspect that's because I'm no longer trying too hard."

"Rachel", 25, who uses Plentyoffish also found she received much more interest after a change of attitude.

"I used to put up pictures where you couldn't see my wheelchair but now I state: 'As you can see, I'm in an electric wheelchair. This doesn't stop me doing what I want and doesn't change who I am, but I'd like to put it out there in case it puts you off! If you're still reading this, then I guess it's a good sign.'

"The first time I actually met up with a guy, it became apparent that he had anxiety problems and didn't get out much – after a few weeks, his neediness irritated me and I finished it.

"Most recently, I met a guy who was lovely to talk to online and we arranged to meet at a bar. I don't go

anywhere without a PA as I can't even hold a drink without assistance but I wanted to go alone, so I had to ask him to help me. He was incredibly quiet initially – it shocks people when they first see how disabled I am,

The first time I actually met up with a guy, it became apparent that he had anxiety problems and didn't get out much – after a few weeks, his neediness irritated me and I finished it

but I'm good at lightening the mood. I saw him a few times but didn't feel a spark.

"I've spoken to what feels like millions of people online. I'm not an

easily forgettable face and often people come up to me in clubs etc and tell me we've 'met' online. Sometimes that might result in a kiss, but none of them have turned into princes."

These unsatisfactory hook-ups are even more prevalent amongst my able-bodied internet-dating friends. Internet-dating with a disability can be a barrier but can also act as a filter, separating the wheat from the cyber-chaff. A lot of people are going to overlook a profile because they see a disability but in my dating experience, on and offline, those that "see" you and not just your "life challenge", are the non-conformist, interesting types you'd want to meet whether or not you're disabled. ■

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Tasting the **spirit** of **Thailand**

During a recent time of civil unrest in the Thai capital Bangkok, **Penny Batchelor** took the opportunity of visiting some less familiar tourist destinations and found herself on the real life set of a Hollywood musical

The Thai King knew a good place for a seaside retreat when he saw one. Back in 1928, King Rama VII decided to make the quiet fishing village of Hua Hin, in 21st century terms a three hour drive south of Bangkok, his summer holiday home. He built the cheerily named Klai Kangwon (Far From Worries) palace there.

This year Hua Hin is celebrating its 100th anniversary. Nowadays a modern seaside resort has built up around the area's five miles of beaches but there's still an atmosphere of old-world charm about the place. Favourite spots on the tourist trail are the animal sanctuary and Monkey Mountain.

The animal sanctuary, a mini zoo,



was set up by royalty to protect the local species of animals and birds. Deer used to roam wild in the Hua Hin area but thanks to over-hunting they are now only found in the animal sanctuary. By Western standards the animals don't have a great deal of room but it's a step in the right direction for Thai conservation efforts.

Animals that have lots of freedom to move are the pesky inhabitants of Monkey Mountain. A taxi drove us past the food stalls and souvenir sellers to the top of the hill. Here, expectant simian eyes viewed us questioningly – did we have any food? The monkeys are notorious for nicking whatever they can get their hands on: sunglasses, bottles of water, packets of crisps ... and can leap with great



Did you know?

The 1956 film *The King and I* is banned in Thailand out of respect for the monarchy.

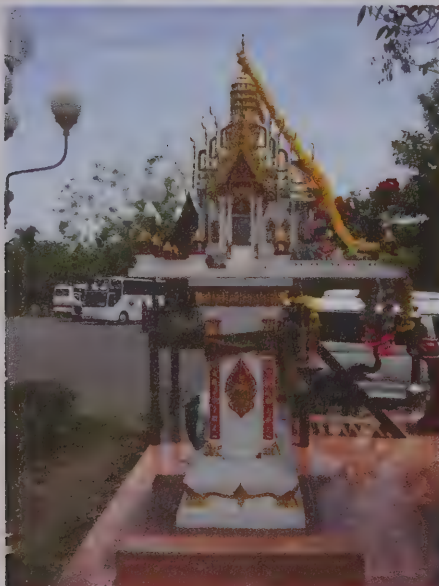
enthusiasm at their chosen booty. Their home is by a temple that I'm told gives great views over the town. I left the monkeys to it to climb the many steps to the top of the temple and basked in the heat of the sun.

The majority of Thais are Buddhist and their beliefs are also intertwined with animism, or spirit worship. When Thai people build a house they believe that this act disturbs the spirits who live there already. To keep the spirits happy they build a little "spirit house" outside the property for the spirits to live in. Woe betide if you build the spirit house in a dank, dingy area at the bottom of the garden: the spirits deserve pride of place, which is usually in a sunny area at the front of the house. The spirit houses may be decorated with mini pieces of furniture and some Thais choose to offer food and drink to the spirits in order to keep them happy.

My quiet and relaxing hotel was just south of Hua Hin in a village called Pranburi. I'd chosen the Evason, a modern hotel complex, in order to have accessible accommodation. The bedrooms are set in two-storey accommodation blocks around the complex and the staff whizzed me round in an electric buggy to whichever part of the hotel I wanted to go to. Reception? Taxi pick-up area? No problem!

On the hotel's television news channel there were pictures of the violence and disturbances going on in Bangkok whilst we were in the country: the red-shirts (protesters against the government) and yellow-shirts (supporters of the government) were opposing each other and clashes had





taken place between civilians and the military. I hastily crossed the Bangkok city tour off my holiday “to do” list.

Instead I went on a trip to see a floating market and another King’s Summer Palace at Phetchaburi. The cheapest way to get around in Thailand is by tuk tuk. These are tiny three-wheeled vehicles that have never seen a suspension system, therefore not great for anyone with a bad back or who is carrying a mobility aid. Pay a bit more and you can hire a comfy, air-conditioned taxi – just

Did you know?

Thailand is nicknamed “The land of smiles”.

agree the fare in advance and insist you don’t want to visit any shops they want to take you to on the way!

The floating market at Damnoen Saduak is the largest in the country. Some of it is for the tourists – there’s an array of textiles, woodcraft and soft drink sellers on the shoreline – but it’s also popular with the locals too.

Vendors paddling dragonboats peddle their fruit and veg, whilst others hope to interest you in souvenirs. It’s a busy and fun place – I tried my hand at haggling after being warned by the tour guide not to pay more than a third of the original price quoted. The seller was much more experienced than me at it though – she stared me down and in this game of wills I ended up paying two-thirds of the price quoted for my souvenir floating market fridge magnet!

Another King who wanted a summer



Did you know?

It is considered extremely impolite in Thailand to touch anyone on the head.

pad to escape to was King Rama IV, who built his on top of a hill in Phetchaburi. I caught a cable car to reach the foot of his palace. The area is now the Phra Nakhon Khiri national museum. King Rama IV is the monarch featured in the film *The King and I*, in which a Western woman comes to teach the King and his family English.

King Rama IV is said to have had over eighty children – they must have been a strapping lot because his land has quite a few stairs to manoeuvre to reach the palace. The cable car is a recent addition – in the King's day his

servants were known to carry him up the mountain to the palace above. No such luxury for me.

The palace's varied contents reflect the King's interest in many cultures, including that of Europe. As well as intricately carved Thai furniture there is English pottery on display. Visitors must take off their shoes out of respect before entering and carry their shoes around in a bag. You even have to do this if you are looking around one of the country's palaces in a wheelchair.

Travelling back to the airport at Bangkok to catch the flight home I came across the only sign of the Thai civil unrest I'd heard about on the news. The taxi driver explained that we were lucky that the airport was open – previously demonstrators against the country's rulers had taken it over and prevented flights from taking off or landing.

"Government no good!" he said animatedly. "Government corrupt!"

I sincerely hope that politics doesn't prevent tourists from discovering Thailand's charms for themselves.

Don't miss:

Trying the whole Thai curry traffic light – red, green and yellow curry.

A cheap foot massage by the beachfront – expect to pay about £5 for an hour.

Browsing local markets for souvenirs – Tiger Balm is particularly recommended.

How to get there:

Penny travelled with Virgin Holidays from London Heathrow to Bangkok. Many other companies also offer package holidays to Hua Hin.

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There are many reasons why disabled people can find books inaccessible. But Amazon's e-book reader has found several solutions and put them in one slim package, **Ian Macrae** says

Dexterity issues may make books difficult or painful to handle. Print may be too small to be readable. Dyslexia may impair the ability to make sense of what's on the page. Or, like me, your vision may not allow you to read print at all.

For whatever reason, the battle for better access to books has had to be fought on many fronts. But always the emphasis has been on making books themselves – the physical entities – available in alternative formats: audio, large print, Braille.

Meanwhile, in another part of the sustainably-grown forest, other forces have been at work.

Enter, from left field, iBooks from Apple and Kindle from Amazon. Both recognised the commercial benefits of making books easily and electronically available. In Apple's case, this has meant books being downloadable to a range of their products.

But for Amazon it has led to the development of its very own e-book reader, the Kindle. What's

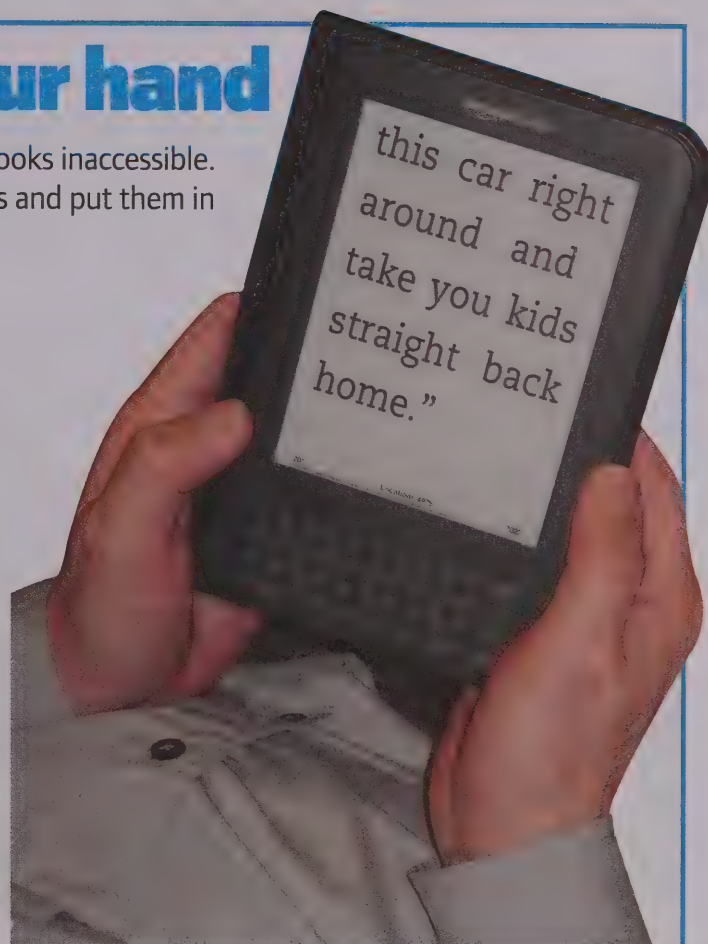
more, a bit of foresight on the part of the company has meant building in a variety of access solutions from the ground up.

For disabled and older people, this has opened up a new set of reading possibilities, and for people like me, that makes it quite simply the most significant development in equality of access to reading since the development of Braille.

Before going further I should say that Amazon hasn't got everything right. The controls on this slim, flat, pleasant-to-hold e-book reader could be more distinguishable from their surroundings by touch: the chevrons on the page-turning keys on either side of the case could be raised, for example, and the keyboard for inputting text could be better.

Against that, you have the choice of reading in a variety of font-size options, right up to 36 point (about the size of the heading on this page).

For those with dexterity issues there's no more faffing with separating and turning pages or trying to keep the book flat enough



to read: the print appears on a page-sized screen with electronic ink making it look very like the real thing.

There's one other crucial feature. "Read-To-Me" and "Voiceguide" features can be turned on, giving the option of navigating the menus and reading texts via very acceptable synthetic speech.

It's a shame that, at present, enabling the speech means that users lose the ability to navigate within a text, but this function, Amazon says, is still at an "experimental"

stage, so we can hope for improvements in the future.

Despite these and other slight niggles, here's one user who'll certainly be reading on.

INFORMATION

Books can be bought or downloaded free of charge, directly from and to the Kindle, or direct from the Kindle store online. More info on the Kindle Wi-Fi and 3G (£111 and £139 respectively) from amazon.co.uk/kindle

helen dolphin



Norwich blue badge victory



In the face of arguments that charging for Blue Badge parking represented equality, **Helen Dolphin** took the view that in fact it's discrimination

In 2009 Norwich City Council announced that they were revising their policy on parking charges and that Blue Badge holders, who had previously been entitled to free parking in council car parks, would now be charged the full amount.

The council justified their position by saying that charging everyone the same amount was "equal" treatment of both disabled

and non-disabled people.

Now, I certainly agree that disabled people should be treated equally! And I don't believe that just because you are disabled you can't afford to pay for your parking. But I don't believe that charging disabled and non-disabled people the same is "equal". In fact, I would argue that to charge Blue Badge holders the same to park as non-disabled people is in

fact discriminatory. This is because the majority of disabled people take longer to get around the shops, and therefore end up paying more to park.

As soon as Norwich City Council announced their policy change my colleagues and I at Mobilise opposed the council's decision, and in various meetings with council representatives over the last 18 months we have done our best to persuade them that this decision was wrong. Sadly, these face-to-face meetings with council members did nothing to convince them that it was unfair to charge disabled

people the full price for parking. It wasn't until me and four other disabled people, with support from Wake Smith & Tofields solicitors, decided to take action under the Disability Discrimination Act and the new Equality Act 2010 and bring a legal case against them that the council finally agreed to change their policy.

Personally I feel that it should never have got to the stage of involving solicitors. If the council had just taken a more common-sense approach and listened to us when we first approached them about the

issue, a lot of time and money could have been saved all round. I am therefore delighted to report that after lengthy consideration the council is at last willing to make a concession for Blue Badge holders parking in council run car parks. Instead of charging Blue Badge holders the same rate as non-disabled people they now allow people who hold a Blue Badge to get an hour's free parking for every hour they buy.

Norwich is now the second council to have

faced legal action concerning discriminatory parking charges. Last year Lincoln Council were also

The majority of disabled people take longer to get around the shops, and therefore end up paying more to park

forced to change their policy after they too were brought to task. I understand that councils are trying to save money wherever possible,

but as these two councils have discovered, bringing in discriminatory charges is not the way to do it.

Martin Harvey, Partner at Wake Smith & Tofields said: "We are delighted with the outcome here in Norwich to assist Blue Badge holders. The firm's previous work in Lincoln with (local resident) Matt Smith has highlighted an injustice many Blue Badge holders are experiencing across the county, and the case here in Norwich is unfortunately now another case to add to that list. We would urge

anyone experiencing similar difficulties to come forward and contact their solicitor."

For the last year many disabled people in Norwich have either been put off coming into their city to shop or have paid more to park than they should have. Of course, there are still many improvements that need to be made in Norwich and other towns across the UK – better provision of accessible parking spaces and public transport would be nice! – but I hope that this victory is a small step in the right direction.



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Mills: downhill all the way

Former model Heather Mills has moved a step closer to realising her ambition of competing in the Paralympics after being offered a trial with the British disabled ski team's development squad.

Mills, who has been seen most recently on reality ice-skating TV shows on both sides of the Atlantic, is hoping to qualify for the 2014 Winter Paralympic Games which will take place in Sochi, Russia.

The ex-wife of former Beatle Sir Paul McCartney became disabled in 1993 following a motorcycle accident.

While a place in the development squad does not guarantee progression into the full squad, many members do often progress to become competitive skiers.

British disabled ski team manager Dave Chugg played down the development, but said that Mills would have every opportunity to demonstrate her ability.

"Heather is only at the first stage of a journey that we hope will lead to her becoming a full squad member," he said.

"She has made clear her ambition to represent Great Britain in adaptive ski racing



and approached the British disabled ski team to try out for our development squad.

"At a recent assessment in an indoor ski slope, she demonstrated that she responds well to coaching and is capable of adapting her skiing in response to coaching direction.

Chugg said that Mills would be put on an intensive

training programme designed to prepare potential skiers for the reality of a competitive environment.

"During the trial period with the development squad she will have the opportunity to develop her skills and follow a set programme both inside and outside of our squad setting.

"This will allow us to

judge her progression from her current standard of being a very good recreational skier towards becoming a racer.

"At the end of that trial period we will make a further assessment based on how far she has improved and on her comparative performance with established racers and other development skiers."

Having recently just turned 43 years old, Mills would normally be considered too old for a place in the development squad. However, Chugg says that they have made an exception due to Mills's physical and mental conditioning.

"She has been invited onto the development team for the trial period because she is outside the usual age and ski profile for the team. However, she has shown good levels of fitness and determination."

Chugg denied that she would receive any preferential treatment due to her high media profile.

"When working with our squads, Heather will be treated the same as any other team member in terms of our expectations on and off the slope," he said.

Laurens quits Paralympic show ring

Paralympic gold medallist Simon Laurens has announced his immediate retirement from international para-equestrian dressage.

Laurens, who won team gold at the 2008 Sydney Paralympics along with an individual silver in freestyle dressage, said personal reasons had forced him to make the decision to step down from competition.

"This has been a very difficult decision and I have thought very carefully for a

number of months before making this announcement," he said.

"For personal reasons competing at international level is becoming more and more difficult.

"I have also been looking very hard for a successor to my current ride, Ocean Diamond (Derek), for the last 12 months and have tried some lovely horses, but have not found a horse that I believe I can win a medal with in London 2012.

"It has become increasingly difficult for me to carry on competing in the current global climate and I have therefore made the very difficult decision to hang up my international boots. I intend to remain involved in the sport and help promote para-equestrian dressage."

British Equestrian Federation (BEF) Performance Director, Will Connell, said it was a "sad day" for para-equestrian sport.

He said: "Not only has

Simon proven himself an outstanding athlete, winning medals for Team GB at Paralympic Games, European and World level, Simon is also a fantastic Team member. He gives freely of his time to help promote his sport and encourages others to try riding.

"He always has a smile on his face and a ready quip that helps maintain a very positive and enjoyable team atmosphere. We will miss him in the Team and the World Class Programme Squad but I hope that we will see a great deal of him."

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Behind the scenes at **Bamboo Grove**

Bamboo Grove is the first novel by Romy Wood. In among the rich variety of subtly drawn characters and evocative atmospheres, **Ian Macrae** discovers that mental health is one of its central themes

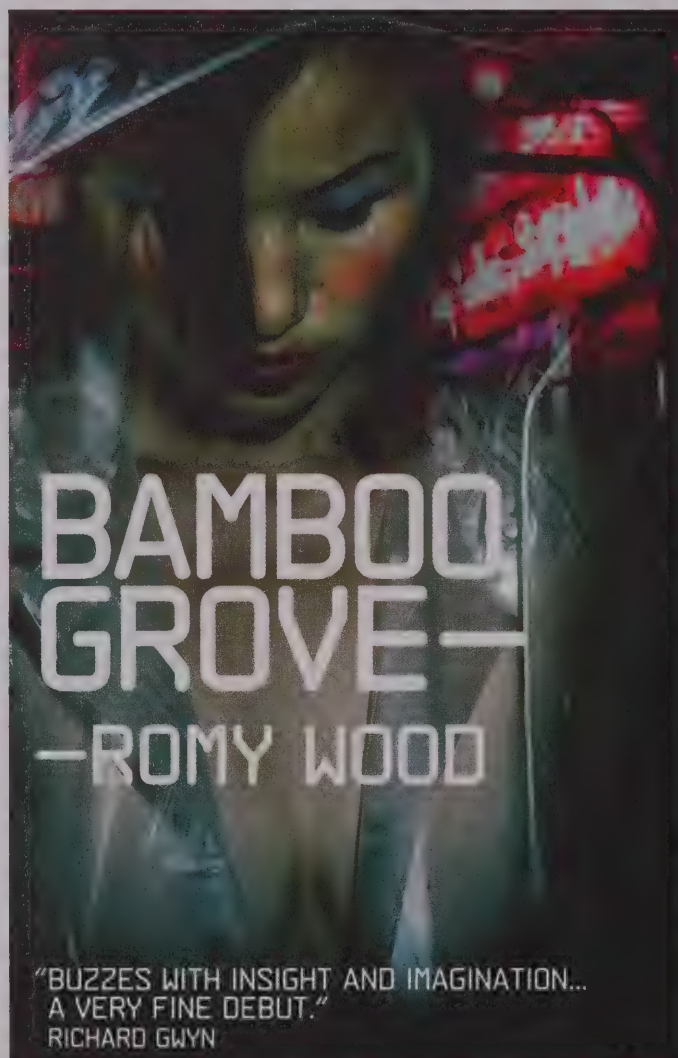
Reading Romy Wood's first novel is rather more like watching a TV show than reading a book. A number of plotlines develop in parallel in short scenes intercut with each other as the action shifts from London to Bangkok; characters move in and out of each other's lives; even time doesn't pass in a linear way.

One thing which is central to the plot, however – perhaps it's the glue that ultimately sticks it together – is the mental health of one of the main characters, Jessica.

She has bipolar, a condition she shares with the book's author. So it's not surprising that I begin by asking Romy Wood that most banal of questions, to what extent is the book autobiographical.

"It's a first novel, and lots of first novels are autobiographical," she says while acknowledging that this fact then leads to another obvious question.

"When you say it's autobiographical, you might think, well, which



character is the author?"

And the answer to that question?

"I think I'm in more than one character. I think it's very difficult to write a character that hasn't got

anything you can identify with. So it's a case of which characters have got the most of me in them. But I'm definitely mostly in Jessica."

While it would be simplistic and a little

dangerous to come to that conclusion on the basis that the author Romy and the character Jessica share a mental health condition, that fact is material. But there are other similarities. Both, for instance are mothers: Jessica gives birth as the plot unfolds in Thailand to her daughter Yin-Yang, and it's their relationship which is perhaps the central one in the book.

But it's difficult to discuss something with a disabled author whose work contains a character with the same condition without addressing the importance of that condition – bipolar – to both book and author.

To the reader, particularly to a disabled reader, bipolar may appear to run through the plot like lettering through a stick of rock or, more appropriately, like an impairment runs through DNA. But would Romy Wood herself confirm that impression?

"I wouldn't say it's a central feature of the book, but it's where it began in that the first scene I wrote was because I asked myself what must it be like to have

a bipolar mother. So I wrote this scene from the point of view of Yin-Yang watching her mother and how that feels to her and the rest of the plot developed around that relationship."

As we talk, it emerges that Romy Wood (pictured right) is somewhat out and proud about her condition. She has definite views on the kind of quiet proselytising she does attempting to confound people's stereotypes of how someone with bipolar is likely to live and function. This emerges when I ask her whether it was important for her to write a book which included a character with bipolar.

"Probably," she admits, "I'm interested in exploring mental health, and I'm interested in exploring emotional intelligence more than mental health."

"I'm kind of vocal about being bipolar because I think it helps if people meet intelligent, professional, functional people and say, 'Oh look, here's someone who spends time in psychiatric establishments and yet they function in society and are a good parent and are a professional' and so on. The more people that you do that with, the more people are going to be increasingly comfortable with



the idea that having a mental health condition doesn't mean being isolated in some way or excluded."

She is, however, wary of the trap that she saw, for example, the movie *Rain Man* create for itself and its

To the reader, particularly to a disabled reader, bipolar may appear to run through the plot like lettering through a stick of rock or, more appropriately, like an impairment runs through DNA

viewers. The notion that the character in some way defines, or at least typifies the condition.

"It's not a book that aims

to promote knowledge or interest in bipolar as such. But I think that's such a big part of me and that's why it probably became such a major strand."

So taking that point, I wonder whether what she's trying to say is that the book isn't flag-waving.

"There are two things here. There's what I say and what the book says. So I guess I flag-wave a bit if I'm chatting to someone, but in terms of the book, Jessica is a different character from me. She's more demanding, more dependant, and perhaps copes less well a lot of the time than maybe I do. So I don't think the book is flag-waving.

"It's a book with a

character with bipolar in it and it is a bipolar book, but it doesn't claim to define that in any way."

It's also a book full of subtle characterisation. No one is wholly good nor wholly bad. There's Moses, a definitely dodgy, almost fake Buddhist monk whose sole aim in life appears to be to use his position to sexually exploit as many women as possible. But he's more complex than that says Romy Wood.

"Moses is not an entirely bad character. He grants people's wishes. He does it cynically and he does it for self-promotion and because he finds the whole thing entertaining, but he does grant people's wishes."

What then does Romy Wood regard as the central message of the book?

"I don't think it's got one single message. My children say it's like a soap opera, because you just explore these characters, these interactions, these societies."

• The *Bamboo Grove* by Romy Wood is published in paperback by Alcemi books. Price £8.99. Alcemi.eu

→ Up-to-the-minute listings

For all the latest arts listings visit www.disabilitynow.org.uk/entertainment/arts

webwatch

A sense of DotComUnity

dotcommunity.org.uk is a fully accessible directory of services, events and activities across the UK. **Annie Makoff** checks it out

If the word "directory" makes you yawn, think again. This online resource for disabled people actually serves a useful purpose. And what's more, it's socially-orientated. It relies on you, me, and her over there, to make it what it is.

And what it is, is bloody brilliant. Users select their desired location on a clickable map which brings up four colour-coordinated main buttons such as 'Disability Directory' or 'What's on in your area'. Buttons like the 'Disability Directory' button brings up further colour coordinated sub-categories such as 'Community Services', 'Employment' or 'Housing/Home & Supported Living'. These include additional sub-categories, but don't panic – everything is so perfectly organised that the reams of sub-categories actually make searching for a specific thing really easy. Rather than having to search laboriously through generic lists in the housing category, if what you actually want is home help



listings, you can easily find them, using the finely-tuned sub-categories which narrow down search options through every button click.

Rather than having to search laboriously through generic lists in the housing category, if what you actually want is home help listings, you can easily find them

Supporting every element of this highly organised community is a rather quirky feature. Every word on the website is linked to the Point system, a paid-for augmentative software

developed by Widgit-online. Hover the mouse over any word throughout the website and the software generates a picture of the word's meaning. Designed with people with learning difficulties in mind, it is also ideal for those learning English and those who struggle with reading and communication for other reasons.

Listings in both the directory and the events & activities section are added and rated accordingly by registered users. The higher rating a listing has, the

higher up it appears in the search directory.

A slight irritation for the registered user however, is the homepage itself. Users are unable to log in and access the members' area (where they can write a review or add a listing) until they have selected a location on the map at the beginning.

In addition, because the site largely relies on user participation, there are several gaps in service listings in areas of the UK where there are very few registered users, especially in the South Yorkshire and Norfolk areas. Oddly, this is not the case for the area around the Scottish Highlands.

Yet the gaps do not affect the usefulness of the site as a whole, due to the sheer number of comprehensive listings elsewhere. And paradoxically, because it is user-generated, the gaps are not likely to stay empty for long. Clearly, the more people that know about the site (and actually use it), the better it will become.

• Visit dotcommunity.org.uk

→ Have your say

- write to us Disability Now, 6 Market Road, London N7 9PW
- email us editor@disabilitynow.org.uk
- phone us 020 7619 7323

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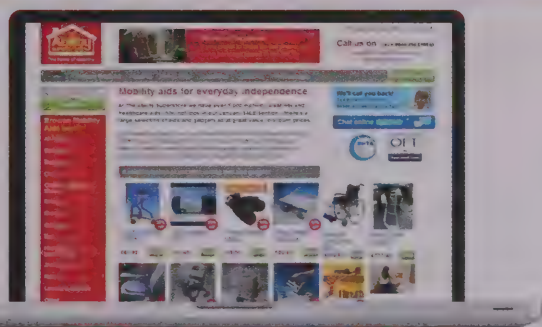
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worklife

I'm a Children's Nurse and work on an oncology ward at Great Ormond Street Hospital.

Before I started this job, I spent just over a year at the Evelina Children's Hospital where I worked on general, renal and cardiac wards.

Throughout my training I had a really bad time and was treated unfairly because of my disability. But since I started working the staff have been amazing and treat me no differently to any other nurse. It's been absolutely brilliant, I've loved every minute of it.

I had a kidney transplant aged seven and I'd been on dialysis for four years before that. I've spent a lot of time in hospital and nurses have been like my second family. I wanted to be a nurse so I could do the same for other children and I thought that my knowledge of spending time in hospital would be really useful too.

My job involves monitoring patients' test results, giving them medication and attending to their hygiene needs. But it's also important that their experience of being in hospital is not a horrible one, so I also spend time playing games and making them laugh too.

Some children are in for a long time so their parents need a lot of emotional



At home on the ward

As a child **Rachael Johnson** had extensive experience of hospital from the patient's point of view. She's now using that experience to inform her work as a nurse on a children's ward

support. They often need a lot of teaching too so that they know how to care for their children at home.

Sometimes the children say "you're too small to be a nurse" and I find it hilarious. They don't mean it in a nasty way, it shows that they're inquisitive and it's good for them to pick up on it. I laugh with them which I suppose is a good way to build a rapport and

develop a fun relationship with them.

There are things that are too high for me to reach but I wouldn't say that there's anything that I can't do on the ward; I've found ways to

adapt from such a young age that it's easy now. There are steps to climb on to reach medication on high shelves in store rooms, I use a trolley if I have to move a stack of heavy boxes and the beds move up and down so I can change the bedding easily.

I've spent a lot of time in hospital and nurses have been like my second family. I wanted to be a nurse so I could do the same for other children

The one most important characteristic you need to be a good nurse is passion for the work. My shifts are twelve and a half hours and you can't give good patient care if you don't enjoy your job. Nursing is something you either want to do or you don't and if you're not sure it's something you want to do, I don't think you'll make a good nurse.


• Rachael Johnson was talking to Sunil Peck

RACHAEL JOHNSON: CAREER PATH

- 2004 – Left La Sagesse school in Newcastle with A-levels in maths, accounting and geography.
- 2009 – Graduated with a

degree in Children's Nursing.

- 2009 – Started working at the Evelina Children's Hospital.



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For further details please contact **DEBBIE WESTMORELAND** or **JESSICA LEWIS** in the School of Sociology and Social Policy at the University of Leeds, LS2 9JT.

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2004(54)	Renault Kangoo 1.6 Authentique, auto, 27,000 mls	£7,195
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DN DEADLINE

March 2011 published 22 February. Classified deadlines: Booking: 31 January. Copy: 2 February

backlash



No time to stand and stare

There's more to a starrer than meets the eye, says **Paul Carter**

I get stared at a lot. An awful lot. Even when I'm asleep. I'd say I probably get more viewers in one day than a repeat of *Terry and June* on ITV4.

It's been such an omnipresent part of my life for so long that the vast majority of the time I don't really notice it, or at the very least, have learned to tune it out. The one situation in which it regularly features on my radar though is when I'm in confined spaces with other people, like on public transport. You can't fail to notice people staring at you on public transport in London, mainly because making eye contact with ANYONE in any circumstances whatsoever is to mark you out as some sort of Dickensian villain.

Therefore, most mornings, I notice at least several times in a journey that I'm being gawped at from various quarters along the way.

The thing is, not all starers are the same. After years of anthropological research on the ground, I've categorised them into three distinct types – each employing their own tactics, methods and reactions.



First up, and probably most common, are the Subtle Starers. I don't have a problem with these, after all, we've all been one at some point, there's no shame in it. Your mum's probably one. These will look out the corner of their eye, for as long as they can – until you catch them. Then they shuffle awkwardly or pretend they were reading the paper and that's that. Like ships in the night. A fleeting engagement and it's over.

Then you get the full-on flabbergasted. These will fix their eyes on you as if they've just discovered the secret of creation. You'd

think these were the worst, but they're not, you can actually have fun with these. I consider it my life's mission to try and defeat this worthy foe, but after years of bringing out my whole arsenal, I've yet to find a chink in their armour. Staring back, smiling, performing Wagner's entire Ring Cycle, nothing works. This group is also interesting in that it has sub-categories. These vary in scale from "holy-batshit-what-the-hell-is-that" to "utterly agog". The latter is rare, which is good as it is potentially fatal.

Perhaps surprisingly, the worst kind of gawper is: The

Repetitive Glancer. Now I don't mean to be rude, but I'm sorry, these people are just plain weird. They exhibit all the characteristics of the Subtle Starers, except, as the name suggests, they keep coming back for more. It's like they love getting caught. Like it's some sort of odd battle of wits. Actually, I'm weirding myself thinking about them. Either that or I'm totally misunderstanding them and they're just crushingly shy people trying to come onto me but find it difficult to make eye contact.

And on that note, I'm off home. I could do with the attention.

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